

# Environmental Public Health Tracking Conference Wyndham Philadelphia | March 24-26, 2004

# Developmental Disabilities: Surveillance, Databases, Data-sharing, and Environmental Associations

Plenary and Concurrent Session Abstract Form

#### Moderator:

David R. Johnson, MD, MS, DABT, FACOEM, Executive Medical Director, Division of Environmental Health, Florida Department of Health, State Environmental Epidemiologist

#### **Presenters:**

Kim Van Naarden Braun, PhD, Epidemiologist, Developmental Disabilities Team, National Center on Birth Defects and Developmental Disabilities, Centers For Disease Control and Prevention

<u>Developmental Disabilities Surveillance: Methods and Results from the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)</u>

Keith G Scott, PhD, Professor of Psychology and Pediatrics, University of Miami The University of Miami Developmental Disabilities Database and the Value of Department of Education Data

Beverly A. Dozier, JD, Privacy Rule Coordinator, Centers for Disease Control and Prevention Epidemiology Program Office, Office of the Director

The Family Educational Rights and Privacy Act (FERPA): Challenges in data sharing

Frank J. Bove ScD, Senior Epidemiologist, Division of Health Studies, ATSDR Environmental Etiologies Associated with Developmental Disabilities and the Brick Township, NJ Autism Cluster Investigation: Challenges in Identifying Environmental Etiologies

## **Session Abstract:**

This breakout session will focus on Developmental Disabilities with regards to the following: surveillance of select types of developmental disabilities; creating and managing databases that can be used in health tracking; understanding the Family Educational Rights and Privacy Act and how this act interplays with data sharing; and discussion of the challenges involved with linking environmental exposure with health outcomes.

Presenters are experts in their area of discussion and will share their experience regarding the Metropolitan Atlanta Developmental Disabilities Surveillance Program, the University of Miami Autism and Developmental Disability Monitoring Database, the Family Educational Rights and Privacy Act, and the Brick Township, NJ, Autism Cluster Investigation.

Interdisciplinary synergy will facilitate understanding of issues involved with Environmental Public Health Tracking as applied to developmental disabilities.

### **Learning Objectives:**

- 1. Familiarization with the epidemiology of select developmental disabilities
- 2. Understanding the development of health outcome databases
- 3. Working with legal issues of the Family Educational Rights and Privacy Act with regards to data sharing
- 4. Recognizing the challenges of linking environmental agents with health outcome data